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Risk and trust in vaccine decision making

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Abstract: Vaccines are widely hailed as vital, safe, and cost-effective public health interventions that save lives and protect health. However, from the development of the first smallpox vaccine at the end of the eighteenth century until the present day, the legitimacy and safety of vaccination has frequently been challenged. Individuals making choices about vaccination have to evaluate reports, often contradictory, about risk. The ways that parents evaluate these reports and make decisions are crucially informed by trust. This paper examines and compares public evaluations of risk and the role of trust in three historic vaccine controversies: the implementation of the global smallpox eradication campaign, the debate over the whooping cough vaccine in the 1970s and 1980s in Great Britain, and the current debate over the MMR vaccine in Britain. The discussion of the MMR controversy will draw upon my recent fieldwork interviewing parents about the vaccination decisions they have made for their children. Parents balance a number of potential risks against one another and choose which risks they are most concerned about. In addition, the importance of herd immunity to successful immunisation programmes allows for an investigation of how individual and collective risks and benefits relate to one another. These issues are only recently beginning to be incorporated into the literature on risk, trust and sociocultural theory.

1. Introduction

1.1. Vaccines are widely touted as vital, safe, cost-effective public health interventions that save lives and protect health. For instance, the WHO, on its `Advocating for Vaccines' website (WHO, 2004), declares: `There is irrefutable evidence that vaccines save lives, and there are many positive achievements to highlight - a large part of the world's population has been immunized against terrible diseases; smallpox has been eradicated, and one of the current scourges, polio, is close to eradication.' However, from the inception in Europe of the practice of vaccinating individuals to protect them from later, more severe, infections, the process generated controversy. To make a significant public health impact, the use of vaccination had to be widespread, so governments often became involved in introducing measures to ensure that large segments of the population complied with the vaccination regime. Greenough (1995) describes the street riots and other struggles that occurred in 19th century America and Europe over compulsory vaccination laws, and points out that such resistance is by no means unique to the early vaccination campaigns:

Yet the potential for resistance is always present, because encounters with government vaccinators are never about immunization alone. Public health measures derive their authority from the police power of the state, and people do not lightly offer themselves (or their immune systems) to government, even when its authority is legitimate (ibid, p. 633).

1.2. The legitimacy and safety of specific vaccines, or of vaccination in general, have been challenged in many different contexts. Evaluations of often contradictory risk reports, and trust - in public health institutions, in individual health care practitioners, and in society generally - play key roles in the decision-making process. This paper offers an exploration of the role of risk and trust in public debates and in personal decisions about vaccination. It will first outline some relevant principles about the construction of risk and the role of trust in modern society, and patterns of vaccine acceptance. After this theoretical overview, it will highlight how these principles were at play in three different episodes in vaccination history: the global smallpox eradication campaign, the debate over the whooping cough vaccine in the 1970s and 1980s, and the current debate over the MMR vaccine. This discussion is based on historical accounts (in the case of smallpox eradication), newspaper archives (in the case of whooping cough vaccine) and ethnographic interviews with parents (in the case of MMR

vaccine).

2. Risk and trust in modern society

2.1. How do we make important medical decisions, like whether to immunise our children with a controversial vaccine, in the face of frightening and contradictory reports about risk? Although such decisions are ultimately undertaken by individuals, social context plays a key role in shaping public debates and policies, as well as in forming individuals' notions and decisions about risk. Hence, researchers in the social sciences have long been concerned with the ways in which risk is socially constructed and portrayed.

2.2. One of the most significant works about the social construction of risk is *Risk and Culture, b* y anthropologist Mary Douglas and political scientist Aaron Wildavsky (1986). All risks, they argue, are socially constructed, because identifying a risk requires a particular configuration of ideas about what outcomes would be undesirable, and what conditions put us in danger of experiencing those outcomes. The risks that we choose to be concerned about have to do with what kind of society we want. Douglas and Wildavsky begin their book by asking:

Can we know the risks we face, now or in the future? No, we cannot; but yes, we must act as if we do. Some dangers are unknown; others are known, but not by us because no one person can know everything. Most people cannot be aware of most dangers at most times. Hence, no one can calculate precisely the total risk to be faced. How, then, do people decide which risks to take and which to ignore? On what basis are certain dangers guarded against and others relegated to secondary status? (*ibid,* p. 1)

2.3. Different people worry about different risks, disagreement is deep and widespread, and programmes enacted to reduce risk consistently fail to prevent the worst damage. Expanding science also opens up new realms that we do not understand or know about. Thus, total knowledge is impossible, but would be required if we were really to understand the risks that face us. Even if we had sufficient knowledge, Douglas and Wildavsky go on to argue, ranking risks as a society doesn't work because we don't have agreement on which risks to focus on. Risk is a product of `knowledge about the future and consent about the most desired prospects' (*ibid,* p. 5).

How do we decide which risks to face? We choose the risks in the same package as we choose our social institutions. Since an individual cannot look in all directions at once, social life demands organization of bias. People order their universe through social bias. By bringing these biases out into the open, we will understand better which policy differences can be reconciled and which cannot (*ibid,* p. 9).

2.4. So the identification of risks has to do primarily with a cultural predisposition toward a particular kind of social outlook. Regardless of the specific number of `cultural biases' included in the scheme, the essential point is that predispositions emerging from cultural biases associated with social groupings form the primary determinant for which type of risks - e.g., technological, economic, or socially deviant - people fear. These sorts of differences make it very hard to achieve societal consensus, and acceptable policy decisions, about what types of risks we should be concerned about and how we should use common resources to manage risk.

2.5. Other anthropologists building on the notion that social groupings inform notions of risk (though not always explicitly) have noted fundamental discordances between `expert' and `lay' conceptions of risk. For instance, Sandra Gifford (1986) highlights the ambiguity of risk conveyed by a diagnosis of benign breast disease (an identified risk factor for breast cancer). 'Epidemiological risk' is framed in terms of `relationships which are objective, depersonalized, quantitative, and scientifically measured' at the level of the population. On the other hand, 'clinical' and 'lay risk' are lived and experienced at the level of the individual. Gifford describes the difficult process of translating epidemiological risk into clinical and lay risk. For a patient with benign breast disease, risk is an uncertainty about how much danger she is in, anxiety about whether her `high-risk' status will lead to disease, and often the need to make some decision about how to manage the risk.

2.6. The German sociologist Ulrich Beck has also enjoyed widespread influence in the social sciences, with his work on the *Risk Society* (1992). Beck describes our current era as the `risk society' of `late modernity', in which the modernisation process has created risks that are spinning out of control, so that we must be increasingly preoccupied with how to live with or change the risks generated by industrialisation. The risks of late modernity are both qualitatively and quantitatively different from risks faced by previous generations: They are in many ways invisible (they `typically *escape perception* and are localized in the sphere of *physical and chemical formulas* ' (*ibid,* p. 21)), yet carry a previously impossible potential for catastrophe and irreversible harm. Now it is possible to imagine, as a direct result of scientific exploitation of nature and industrialization, that humanity could bring about its own total destruction, for example in a nuclear war or by such massive environmental pollution as to make the earth uninhabitable.

2.7. Beck's definition of risk places it exclusively in the domain of modernity: ` *Risk* may be defined as a *systematic way of dealing with the hazards and insecurities induced and introduced by modernization itself* ' (*ibid,* p. 21). Because the new risks are largely invisible, knowledge plays an increasingly important role in the risk society, as people work to establish causal links between seemingly unrelated phenomena (e.g., use of the pesticide DDT and the health of babies who may be found to be receiving residues of the pesticide in their mothers' milk; we could also include here the current efforts in the UK

to link the observed rise in autism and the MMR vaccine). Risks must be believed, because they can't be experienced as such, and so important debates emerge about what risks we, as a society, are willing to accept, and what risks we are willing to believe in. However, the hazards represented by these risks continue to affect us, whether we believe in them or not. Competing rationalities and risk definitions become entangled in a debate about how we wish to live. Scientific and social rationalities end up talking past one another:

Social movements raise questions that are not answered by the risk technicians at all, and the technicians answer questions which miss the point of what was really asked and what feeds public anxiety (ibid, p. 30)... The social effect of risk definitions is therefore not dependent on their scientific validity (*ibid,* p. 32).

2.8. In this light, risks have profound social and political consequences, independently of their physical reality. What matters is public belief in, and anxiety about, risks, for which governments and industries are held accountable.

The ecological and health consequences may be as hypothetical, as justified, as minimized, or as dramatized as they wish. Where they are believed they have the social, economic, political and legal consequences just mentioned. To put it in the well known sociological sequence: if people experience risks as real, they are real as a consequence . (*ibid,* p. 77)

2.9. Thus, the role of risk in modern society is related to the erosion of public trust in governments and science as society becomes increasingly complex in late modernity. Closely aligned with Beck's work on late modernity is Anthony Giddens's theory of trust. As societies become more and more complex, we are increasingly reliant on trust - in systems and in strangers. We cannot personally undertake all of the cognitive tasks required to manage our day-to-day lives, so we delegate these tasks to others on the basis of trust. Risk and trust are closely linked, because we are reliant on others, and must trust them, to protect us from risks. However, this trust is strongest within social groups, and distrust often prevails between one social group and another (e.g., government regulators and worried citizens). Earle and Cvetkovitch (1995) argue that we need to move beyond this form of social trust, to a state of `cosmopolitan social trust,' which relies on flexibility, communication across social boundaries, and imagination to find common values *across* different social groups and develop solutions to problems that were previously beset by inter-group divisions.

3. A model of vaccine acceptance

3.1. Immunisation is a pivotal component of global efforts to reduce the threats to life and health posed by communicable diseases. At the 1978 World Health Organization conference in Alma Ata, a new strategy for public health, termed Primary Health Care (PHC), was embraced. The vision for PHC was based upon a broad approach to public health, in which small-scale projects, developed in participation with local communities, would predominate. However, critics argued that the PHC strategy was too ambitious, idealistic and inefficient; they developed a competing strategy known as Selective Primary Health Care (SPHC). Proponents of SPHC argued that a more cost-effective approach, which would save more lives, was to target scarce resources to select diseases which were associated with the highest mortality and morbidity and had low-cost technologies available for prevention and treatment (Soc. Sci. Med., 1988). Immunisation received particular emphasis, with the implementation of programmes such as the Universal Programme on Immunisation (UPI) and the WHO's Expanded Programme on Immunisation (EPI), which sought to eliminate or dramatically reduce the prevalence of six immunisable diseases - tetanus, pertussis, diphtheria, tuberculosis, poliomyelitis and measles - around the globe. Thus, the priorities for childhood immunisation were set by top-level international policy makers, rather than by local communities. Such global SPHC measures have therefore been criticised for their failure to respond to local health needs and values.

3.2. One practice frequently used in the EPI campaign to encourage widespread uptake of immunisations is to introduce intensive vaccination campaigns, using widespread media messages and vaccination camps to vaccinate a large number of children in a short amount of time. The reasoning behind the use of such campaigns, which are financially impossible to sustain over a long period of time, is that once the public have been introduced to the benefits of vaccination (in the form of lower rates of illness and suffering) they will seek out such technology on their own. Mark Nichter (1995) has questioned this assumption by distinguishing between `active demand' (in which people would seek out vaccinations, as hoped by the EPI planners) and `passive acceptance' (in which people would accept vaccinations during the campaign, but the demand would not be sustained beyond the end of the campaign).

3.3. Streefland *et al.* (1999) have expanded Nichter's model based on the distinction of active demand from passive acceptance, to identify possible responses to vaccination programmes: acceptance, social demand, and non-acceptance. Acceptance of vaccines exists along a continuum from active to passive acceptance, and may or may not be rooted in a well-informed understanding of vaccination. Social demand, however, is more active and is based upon a perception of some general or specific benefit from vaccination; it is grounded in trust in the biomedical system, and exhibited when parents request vaccinations. Non-acceptance may be either individual (exhibited by a refusal to vaccinate) or collective (exhibited by organised resistance to vaccination). However, Streefland *et al.* noted that these categories are not mutually exclusive. Gradations of acceptance exist, and parents may change from acceptance to non-acceptance. For instance, a parent may vaccinate one child but later refuse to vaccinate a younger child, may stop vaccinating during the course of a child's immunisation course, or may refuse a specific vaccine but accept others. At the aggregate level, these different patterns of vaccine acceptance and non-acceptance lead to `dynamic configurations of fully immunised, partially immunised, and non-immunised children' (*ibid,* p. 1710).

3.4. In the three case studies that follow, I will demonstrate how ideas about risk, informed by trust and distrust, impact on people's acceptance and resistance to vaccinations.

The global smallpox eradication campaign (1960s)

3.5. In 1966 the World Health Organization launched an ambitious (and, in the end, successful) programme aimed at eradicating smallpox from the world. The eradication of smallpox is often touted as one of the greatest achievements of modern public health, but vaccinating enough people to eradicate the disease required overcoming significant resistance in different parts of the world. One reason for resistance, particularly in areas of South Asia, was that an indigenous practice of variolation, or inoculating people by scratching material from infected smallpox sores into the skin, already existed; thus, people did not perceive any need for Western smallpox vaccines (Streefland *et al.* , 1999). This resistance to immunisation was often overcome with heavy-handed coercive techniques. Greenough (1995) describes the intimidation and coercion used by physician-epidemiologists employed by the United States Centers for Disease Control in the WHO smallpox eradication campaign in South Asia. These techniques included containing individuals who had not yet been vaccinated until they consented to vaccination, and intimidating host-country medical staff. Although in the short term, these techniques were hailed as hugely successful because they resulted in the elimination of smallpox, in the long term, these events have probably contributed to problems of trust in health workers.

3.6. Such trust is a vital component of campaigns that aim to control, rather than eradicate, diseases, because such campaigns require widespread public acceptance sustained over a long period of time. In these cases, the diseases are still present in the population, but are prevented from spreading because most people in the population have been immunised. However, when trust in the public health officials promoting vaccination fails (or is undermined by coercive techniques considered unacceptable to the public), and uptake of vaccination is affected, then disease outbreaks and epidemics may be seen.

4. The pertussis vaccine scare (1970s-1980s)

4.1. In the 1970s and 1980s a tremendous controversy emerged in Great Britain over the safety of the whole-cell pertussis (whooping cough) vaccine. The pertussis vaccine controversy has been called `the most significant setback for the cause of immunization since the smallpox vaccine debates of the previous century' (Baker, 2003, p. 4003). Although the debate originally emerged in Britain, it ultimately spread to Japan, the United States, Soviet Union and Australia, leading to sharp declines in pertussis vaccination followed by a series of whooping cough epidemics.

4.2. The controversy emerged with the publication of an article describing a small number of children believed to have been damaged by the vaccine (Kulenkampff *et al.* , 1974). In this case, the article was concerned with 36 children being treated at the Hospital for Sick Children at Great Ormond Street, who had suffered severe neurological complications in the aftermath of DTP immunisation. DTP is a combined vaccine for three diseases (diphtheria, tetanus and pertussis). Because the pertussis component of the triple vaccine used at the time contained bacterial cells and was more reactogenic than the diphtherial and tetanus toxoids also present in the DTP vaccine, this component was assumed to be the culprit in reactions following immunisation with DTP (Department of Health and Social Security, 1977, p. 20-21). Pertussis was recognised to be particularly harmful to infants under six months of age, below the age at which DTP immunisation was administered at that time. Thus, the primary benefit of pertussis immunisation was not to the children being immunised, but rather to the younger infants they might come in contact with, by providing herd immunity. The very serious complications thought to be associated with pertussis vaccine therefore seemed especially salient to many parents, who felt that their children were being put at risk for the sake of protecting somebody else (Ashley, 1977).

4.3. A parents' advocacy group, the Association of Parents of Vaccine-Damaged Children, was formed to provide support for parents and to focus public attention on the issue. In addition to ensuring a prominent media profile and campaigning to place pertussis vaccine high on the nation's political agenda, the Association of Parents of Vaccine-Damaged Children also submitted cases of children with neurological damage allegedly caused by the pertussis vaccine to government medical panels for investigation. As a result, the Government in 1979 passed the Vaccine Damage Payments Act, resulting in the lump-sum payment of £10,000 to each of 638 people allegedly harmed by whooping cough vaccination (Healy, 1978; Healy, 1980). The medical community initially appeared to be sharply divided over the safety of the pertussis vaccine. The Joint Committee on Vaccination and Immunization (JCVI) met immediately following the article's publication and expressed support for the vaccine, but the government did not take any further action to restore public confidence in the vaccine. Several prominent physicians, including one of the authors of the Great Ormond Street article and even a member of the JCVI, publicly criticised the JCVI's decision to continue to endorse the vaccine. At the same time, general practitioners and health visitors were following much more liberal interpretations of the contraindications to vaccination than the government, so that the vaccine was withheld from many children on such grounds as being `jittery' following a breach delivery or family history of allergies (Hull, 1981; Baker, 2003).

4.4. In 1977, the government launched a series of investigations into the vaccine's safety (Department of Health and Social Security,1977; Baker, 2003). Two advisory panels reviewed individual cases, including those submitted by the Association of Parents of Vaccine-Damaged Children, and a very large case-control study, the National Childhood Encephalopathy Study (NCES), examined the possibility of immunisation as a risk factor for acute neurological illness. While the advisory panels

reviewing individual cases concluded that they could not prove or disprove whether the vaccine caused encephalopathy, the NCES authors reported in 1981 that pertussis vaccine was associated with an increased risk of acute neurological illness, but that the risk appeared to be very low, and that risk of permanent neurological damage was even lower (Department of Health and Social Security, 1981; Baker, 2003). At this point, the government launched a major education and media campaign to increase vaccination uptake. Most physicians seemed to feel the debate had been resolved by this study, but the controversy continued in the legal battle of the parents who believed their children had been damaged by the vaccine. The final legal case, in which the Wellcome Foundation undertook to clear the vaccine's reputation through a detailed critical analysis of the few cases that had led the NCES to the conclusion that pertussis vaccine could cause neurological damage, was ended in 1988, with a ruling against the aggrieved parents.

4.5. The impact of this controversy on immunisation uptake and disease outbreaks was staggering. By 1977, pertussis immunisation uptake was down from 77% to 33%, and some districts even recorded an uptake rate of just 9% (Swansea Research Unit, 1981). In terms of disease burden, at least four significant outbreaks of whooping cough occurred during the course of the vaccine scare. The first of these, in 1979, had 102,500 reported cases throughout the United Kingdom and an estimated 36 fatalities.

4.6. Today, this case is frequently cited in the medical literature as an instance of unfounded, irrational fears having serious public health consequences, and hence of the need for the government and medical establishment to maintain high standards for scientifically evaluating claims against vaccines, and to present unambiguous messages about the safety and importance of vaccination. However, the final example - the current controversy over the measles, mumps and rubella, or MMR, vaccine - shows how this approach also has serious limitations in terms of fostering trust.

5. The UK MMR vaccine controversy (1998-present)

5.1. The MMR vaccine has been the subject of tremendous controversy about risk in the UK, following widely publicised reports that the vaccine may be linked to autism and Crohn's disease (or irritable bowel syndrome). In 1998, gastroenterologist Andrew Wakefield published a paper in the *Lancet* , which described a small group of children who had been referred to his paediatric gastroenterology unit with concurrent developmental regression and gastrointestinal problems (Wakefield, 1998). 9 of the 12 children had become autistic. The paper suggested a possible trigger: the parents of 8 of the 12 children associated the onset of these problems with MMR vaccination. This was reported in the popular media as a scientific claim of a possible link between the MMR vaccine and autism, initiating an impassioned debate about the vaccine's safety. Since then, a mechanism for the supposed link between MMR vaccine and autism has emerged in popular and media discussions, whereby the mumps component of the vaccine somehow works to allow measles virus from the vaccine into the intestine of susceptible individuals; the measles virus then renders the intestine permeable to certain peptides (becoming a `leaky gut'), which then enter the bloodstream and somehow interfere with the central-nervous-system opiods, subsequently disrupting normal neuroregulation and brain development, and causing the autistic behaviour (Wakefield, 1998).

5.2. Although a number of subsequent studies have failed to confirm such risk from the MMR vaccine, the prospect of a child developing autism is so frightening that an uproar of anxiety has emerged among UK parents and in the media. At the same time, MMR confers immunity to diseases that also represent frightening risks. For all three of these diseases, maintaining sufficiently high levels of immunity in the population to prevent the spread of the disease among susceptible individuals (`herd immunity') is a major public health priority. Thus the Department of Health insists that the vaccine is not only safe, but also a vital component of its preventive strategy, and in 2001 launched a £3 million campaign to promote the vaccine as `the safest way for parents to protect their children'.

5.3. A series of three separate vaccinations for measles, mumps and rubella, temporally spaced so as to give children time to respond to each immunisation before exposing them to the others, has been widely perceived as a safer alternative to the MMR. Private clinics have been set up across the country to offer these `single vaccines,' typically at prices around £80 per injection, in addition to any consultation fees. However, there is to date no published work about the relative safety of the triple versus serial single vaccine, and health officials have expressed concern about the safety, efficacy and practicability of this regimen.

5.4. Caught in the middle of this debate are the parents who must evaluate reports of the potential dangers of MMR, on the one hand, and on the other the risk of exposing their children to measles, mumps and rubella by not vaccinating them, or delaying children's immunity to dangerous diseases by opting for the series of single injections. The reports, coming from both sides of the debate, are often very dramatic and worrying. For many parents, this situation presents a bewildering and distressing dilemma. So how do parents evaluate such contradictory information about risk in order to make the decision whether to have their children immunised?

5.5. In the case of MMR, where any decision taken is known to be accompanied by some risk, parents engaged in a process of evaluating and balancing alternative risks, `weighing the risks of vaccinating against the risks of not vaccinating' (*Preetha, immunised with MMR)* . Parents tended to be very explicit about weighing up the risks of vaccination, on the one hand, and the risks of disease, on the other, in a highly rational sort of risk evaluation. However, they performed this evaluation in the face of a large degree of uncertainty about the relative risks and benefits, which made their assessments at times ambiguous and difficult. Furthermore, the calculation took into account far more than simply the relative likelihoods of harm from

vaccinating or from not vaccinating - the risks on either side of this decision represented different types of risk and were thus evaluated differently. Previous experiences or dispositions and strong emotions also played a significant role in parents' evaluation and assessment of the risks involved in vaccinating their children, or not, with the MMR:

So it was the emotion rather than the hard logical fact. You cope with the hard logical fact, the risks of having the innoculation and then there being an epidemic or whatever and my child is suffering with all the possible complications. In terms of probably there was a greater risk to me than the unproven risks of the MMR vaccine. So it was always, you know, a certainty that they would be innoculated. But it was more coming to terms with the emotion of it. (Jane, immunised with MMR)

5.6. The risks that parents feared from MMR vaccination include, of course, the purported links with autism and bowel disease, as well as other side effects (ranging from the mild, e.g., rashes, to the serious, e.g., convulsions) and more nebulous concerns like immune system overload, allergies and depriving children of the opportunity to develop `natural immunity'. Parents were divided as to how important a very small risk of something like autism seemed to be, and on where to place the burden of proof. That is, should the vaccine be presumed to be safe until proven otherwise, i.e., until a link with autism is confirmed, or does the uncertainty point to insufficient research? Does this mean that the vaccine is too risky to be used until more long-term research proves that it is safe?

And then I remember listening to one [report], about the person who initially raised the concerns about the MMR and they said he had only had like 12 people or something. And when I heard that I thought that was just ridiculous, that the risks associated with not having the MMR were probably far greater than the ones associated with having it. (Fiona, immunised with MMR)

And we're not being given, we haven't been given clear and strong evidence that the MMR is safe. (Valerie, immunising separately)

5.7. Between these extremes, most parents recognised that proving or disproving such a link is extremely difficult, and that they have to evaluate the arguments to make a decision in the absence of complete certainty or proof.

5.8. In considering the risks of measles, mumps and rubella that children would be exposed to if they were not immunised, parents evaluated the seriousness and the likelihood of exposure of the three diseases. A number of nuanced factors entered into these evaluations, such as the quality of the child's living conditions and diet (which, if good, might mitigate against possible complications of the diseases) and the overall level of vaccination in the community. In general, parents recognised that falling vaccination rates meant that their children, if unimmunised, were more likely to catch measles, mumps or rubella. In fact, the children of a few parents I interviewed had recently had cases of measles or rubella (though none with serious complications). Another important type of risk that parents perceived from not allowing their children to be vaccinated with MMR was the social risk of being seen as a bad or irresponsible parent. This was particularly the case when parents were unsure about their decision, or placed a high value on being respected by their doctors or health visitors. Being struck from GP patient lists was an extreme consequence of this social risk that many parents feared.

5.9. Public health concern over the currently low rates of MMR uptake stems from the need to achieve high levels of immunity in the population in order to prevent outbreaks of measles, mumps and rubella. This consideration has been widely highlighted in media reporting of drops in MMR vaccination rates. Most parents were aware of the concept, if not the name, of `herd immunity.' Aware of the falling immunisation rates in their community, some parents were particularly keen to immunise their children because they knew that their children were more likely to contract the diseases when fewer in the population were immunised. Contributing to the herd immunity of the population by vaccinating one's own children was seen by many as a parent's responsibility to the community.

5.10. On the other hand, parents also expressed the view that their own children's health and safety was a more important concern than the small contribution to the health of the population that they could offer by vaccinating their children. This did not necessarily constitute a reason to avoid the MMR, but parents who expressed the responsibility to maintain herd immunity as a reason to vaccinate had typically already decided to do so for the benefit of their own children's health, anyway.

5.11. An additional layer of uncertainty complicated the situation. Parents were exposed to contradictory information and claims about the safety of the vaccine from many different sources. So not only were parents uncertain about whether their own children would be adversely affected, but they were also uncertain about whether the risks from the vaccine were in fact real and, if so, what the nature and magnitude of these risks would be. Therefore, seeking and assessing information about the vaccine was a crucial part of the decision-making process.

5.12. The discussions about reviewing information sources and evidence made it clear that parents making decisions about the MMR vaccine for their children were dependent on many other people. People working for government bodies such as the Department of Health formulated policies and advice on the basis of medical and epidemiological evidence. Medical researchers conducted investigations into the safety of MMR and the epidemiology of the diseases it protects against. Other experts evaluated these studies and interpreted them for the public. Many other agents (e.g., reporters, other parents) communicated and reinterpreted this information. In most cases, the arguments about the vaccine took place beyond the realm

of the parents' experience and knowledge. Therefore, the information and advice had to be taken - or not - on the basis of *trust* .

5.13. Because the claims and advice offered by medical experts, other parents and government agencies were often contradictory, parents had to decide whom to believe based on trusting certain people and distrusting others. Trust could not be universal, because trusting one party meant rejecting the advice of another. When parents were unable to trust any of the sources of information and advice about the MMR, they did not know whom to believe. This situation was bewildering, frustrating and overwhelming for such parents:

I think you can just take what everybody says, whatever you read, take it all on board and just have to weigh up how you feel at the end of it. I don't know whether this expert from this university or study, or whatever, I don't know whether that person knows any better than the next `expert'. I think that we just have to take it all on board. That's the trouble really, I don't know which expert to believe. Tony Blair stands up and says this is right, we don't want to believe him either. (Valerie, immunised separately)

5.14. Many parents perceived the MMR debate to be a political issue. The politicisation of the MMR debate was a great problem, because parents tended to report categorically that they did not trust politicians. Government ministers' mishandling of other issues (such as the British BSE crisis) related to risk seriously undermined parents' confidence in governmental pronouncements that the MMR vaccine was safe. And perceptions that politicians had lied about other issues (such as the justification for going to war in Iraq) undermined belief in the Government's integrity. So the Government's emphatic support for the MMR vaccine may have actually diminished, rather than restored, public confidence when the issue became political. Some parents reported that they trusted the Government's decisions only after evaluating the relevant evidence themselves. It seems, then, that one of the crucial functions of trust in modern society - eliminating the need for citizens to become experts in everything by allowing them to delegate responsibility for decisions to others - had broken down in the case of MMR in the UK.

5.15. Across the spectrum of parents' own beliefs or decisions about the MMR vaccine, many parents found the Government's approach to be `defensive' and therefore off-putting. The Government, they said, was too heavy-handed in its approach. Parents wanted the Government to do more to acknowledge uncertainty, as well as the good intentions of parents who questioned its policy on MMR or opted not to allow their children to have it. Many parents felt that government health officials should be more trusting of parents and their capacity to act in the best interest of their own children's health. The Department of Health's refusal to offer separate vaccines, to many parents, was emblematic of this defensiveness and contributed to the problem of distrust. If parents were given more options, then they might be less inclined to believe the Government was `pushing' a dubious or hidden agenda; furthermore, some parents who were not immunising their children might be motivated to do so. This viewpoint was certainly not universal, but it is interesting to note that it was put forward by many parents who fully supported the MMR, as well as by parents who did not.

5.16. Dissociated from government political agendas, medical advice in general was well trusted by the parents I talked to.1 They valued the experience and training of medical professionals. Also, knowing that doctors, n0urses and epidemiologists follow a well-established professional code of practice inspired confidence in their recommendations.

5.17. Personal relationships with particular medical professionals were extremely important for parents' trust. In particular, taking time to listen to parents and attention to `little things' that demonstrated competence and interest in patients' concerns were important bases for trusting relationships between parents and individual health professionals.

5.18. Another very important critique that many parents made, of both medical and government strategies to convince parents to allow their children to be given the MMR, was that they relied on emotional manipulation and exaggerated the potential consequences of not immunising. Appeals to fear were salient because of parents' tremendous emotional investment in their children's well-being. But parents sometimes felt that their strong emotions were being exploited to prompt them into a particular action in a way that clouded rational discussion and decision-making. This feeling of emotional exploitation was very damaging to trust between parents and medical authorities.2

5.19. Disagreement among the medical experts is a frustrating concern for many parents. Although they know that the majority of medical experts have put their support behind the MMR, they also recognise as experts the researchers who suggested the risk of autism. In some cases specialist doctors had recommended against the MMR to parents, so the medical community does indeed appear to be divided. The very strong message from the Department of Health and most GPs and health visitors is often perceived to be merely `towing the party line':

I spoke to my GP about it but I mean I just got sort of party line from him. So that was pretty standard. (Preetha, immunised with MMR)

5.20. Many parents expressed doubts that their questions were being answered honestly, because health professionals risked losing their jobs if they openly discussed their own reservations about the MMR. Financial incentives for GPs to reach immunisation targets were also seen to compromise open discussion. The refusal to offer separate vaccines within the NHS, was very often viewed as being solely a matter of cost. For parents worried that MMR was unsafe, this apparent prioritising of cost over children's health and well-being is alarming. Trust, then, is lost when parents do not feel that they are being

listened to.

I just think that it's, for some reason people in kind of positions of authority advising have a problem with saying `I'm pretty sure.' Because that's what we have to do as a parent... but if they say `There's no problem there's no problem,' you just kind of do immediately get suspicious. (Emma, immunised with MMR)

6. Conclusion

6.1. In the three cases presented here- the smallpox eradication campaign, the controversy about whooping cough vaccine, and the controversy about MMR vaccine- people adopted a range of positions with respect to acceptance of, or resistance to, the vaccines in question. Their decisions were informed by different concepts of risk. These different concepts of risk depend in large measure on trust and distrust (e.g., in governments promoting a vaccine, or in sources of information about the vaccine's safety). Vaccine risk perceptions also depend on culturally informed predispositions toward certain types of anxieties: some people will be more fearful of communicable diseases, while others will be more fearful of the effects of invasive medical technologies. Research on risk and trust in vaccine decision making will contribute to the anthropology of risk by elucidating the processes by which people evaluate and balance competing notions of risk, as well as the ways that individual and collective risks and benefits relate to one another in informing the decision making process.

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1. The exception to this observation is parents who disagreed with conventional medical practices and instead followed one or more alternative medical traditions. But these parents also were generally trusting of the medical advice given by practitioners of their preferred tradition.

2. It should be pointed out that parents also described similar feelings about many of the reports of the problems with autism allegedly caused by the MMR.